



**A HOME CARE SYSTEM IN CRISIS**

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# THE HIGH COST OF LOW WAGES

**A REPORT BY THE  
CONSUMER DIRECTED  
PERSONAL ASSISTANCE  
ASSOCIATION OF NEW  
YORK STATE (CDPAANYS)**

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**OCTOBER 2021**

This report was made possible because of the hard work of a number of individuals. CDPAANYS would like to recognize Julia Battista and Laura Cardwell, who were instrumental in the drafting and design of the report. Kendra Scalia, CDPAANYS Board President, created the survey instrument that has been used for each iteration of the report and was critical in helping to analyze the information gathered.

This report is dedicated to the memory of Fausto Romero, a personal assistant in the Bronx, NY who contracted COVID-19 and passed away due to his efforts to continue working and ensure the safety of the consumer for whom he worked. Fausto, and all of the PAs and consumers who lost their life to this pandemic, will be remembered fondly. This report, along with the effort to enact Fair Pay for Home Care, seek to honor the sacrifice they made.

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## EXECUTIVE SUMMARY

Home and community-based services (HCBS) in New York's Medicaid program have been dramatically underfunded for over a decade. These services, which include home health care, personal care, and consumer directed personal assistance (CDPA), are a critical lifeline for seniors and disabilities who wish to avoid costly institutions and instead live quality, independent lives at home, in their communities.

For years, the Consumer Directed Personal Assistance Association of New York State (CDPAANYS) has been sounding alarm bells about the worsening state of this industry, primarily focusing on how the systemic underfunding of this sector has led to poverty-level wages for workers. To determine the impact these low wages have on the industry, and in particular the consumers who rely on these workers to live independently in the community.

In 2016 and again in 2019, CDPAANYS surveyed consumers to determine the impact low wages were having. In each subsequent report, we have found that these wages were creating a sector in crisis. Consumers reported having difficulty hiring staff, difficulty keeping staff when they could hire, and needing to supplement wages out of their own pocket in order to maintain services.

In the third iteration of this survey, a stark picture came to light. While previous surveys found an industry in crisis, the 2021 version of the survey identified a system in collapse. By every measure, the situation for consumers trying to remain independent has dramatically worsened.

**Key Takeaway: A Home Care System in Crisis. 74% of seniors and people with disabilities are unable to retain home care workers in 2021.**

**A Growing Shortage:** Across every single measure, the real-world situations of seniors and disabled New Yorkers trying to avoid institutionalization is not only worse today than it was just three to five years ago, it is dramatically so:

- 9% of consumers reported that it took them over a year to hire new staff, nearly eight times the statewide rate from 2016.
- Over half of respondents statewide said that when recruiting, the most time consuming portion was "awaiting responses to advertisements or finding a potential candidate who would not turn down the job." Previously, "awaiting fulfillment of medical requirements" far exceeded the length of every other category.
- 20% of consumers reported that all five of their past five PAs quit. Three years ago, this number was just under 4%, while five years ago it was just over 2%.

**The Root Cause — Low Pay:** The wages people can pay their workers, which are entirely dependent on government funding through the Medicaid program, are insufficient to attract a pool of workers:

- Over half of the workers who quit identified low wages as the reason they did so.
- A quarter of consumers - seniors and disabled people poor enough to live on Medicaid - feel the need to supplement worker wages out of their own pocket to try to keep their staff.

Despite multiple warnings from advocates, the Legislature, and providers over the past several years, the previous administration chose to ignore, and even actively deny, these facts, instead continuing with cuts and failing to meaningfully invest in community-based long-term supports and services.

## THE HIGH COST OF LOW WAGES

Across every single measure, the real-world situations of seniors and disabled New Yorkers trying to avoid institutionalization is not only worse today than it was just three to five years ago, it is dramatically so. The wages people can pay their workers, which are entirely dependent on government funding through the Medicaid program, are insufficient to attract a pool of workers. Despite multiple warnings from advocates, the Legislature, and providers over the past several years, the previous administration chose to ignore, and even actively deny, these facts, instead continuing with cuts and failing to meaningfully invest in community-based long-term supports and services.

## RECOMMENDATIONS

A system that has collapsed requires dramatic changes to rebuild it appropriately. This is even more true as New York's population continues to age dramatically, indicating a rapidly escalating need for services that most predict will continue for the next decade.

To address the fundamental issues that have led to the situation in which the state finds itself, it must:

- **Enact Fair Pay for Home Care** - This legislation, sponsored by Senator Rachel May and Assembly Member Richard Gottfried, would invest heavily in home and community based services. It would create a new minimum wage for home care workers that is equal to 150% of the highest minimum wage in a region, currently \$22.50/hr. statewide. To ensure providers can meet these costs, it also has transparency provisions that ensure the state's funds are not used by managed care plans to increase profits, but instead go to providers to meet these new requirements.
- **Ensure adequate reimbursement to fiscal intermediaries** - When the Department of Health changed the reimbursement scheme to fiscal intermediaries, the new administrative per member, per month (PMPM) approach was a "one size fits all" model that did not account for the differences between New York City and more rural, Upstate counties. To ensure FIs can properly administer the consumer directed personal assistance program and protect the integrity of state funds, the PMPM methodology must be adjusted to reflect the different costs of doing business throughout the state.
- **Provide transparent data about the use of home and community-based services** - The only way to determine how many people utilize CDPA, or any home care service, is to go through the FOIL process and then transcribe data, once it is received, into a searchable format that can merge with other reports. Given that the state possesses all of this data, advocates, researchers, and those who rely on the system must be given access to it. To do this, the state should pass A.8173 (Gonzalez-Rojas)/S.7372 (Hinchey), which would require the state to report to the public how many people are using community-based long-term care services across the state, as well as how many hours, on average, their members are receiving.
- **Repeal eligibility and accessibility cuts from the Medicaid Redesign Team 2** - At the beginning of the COVID-19 pandemic, then-Governor Cuomo enacted a series of cuts to Medicaid that will cause significant harm to those seeking to use CDPA or other HCBS services. Harmful eligibility cuts and service alterations that will almost certainly create unnecessary, and deadly, delays to the receipt of services must be repealed, because even if we restore the workforce, the services are not worthwhile if people cannot access them, and do so in a timely manner.

## INTRODUCTION

In response to a worsening workforce shortage in home care, including consumer directed personal assistance (CDPA), the Consumer Directed Personal Assistance Association of New York State (CDPAANYS) surveyed consumers from across the state about their experience with CDPA in late 2016. The results of that survey were published in February 2017 in a report entitled *The High Cost of Low Wages: A decade's worth of neglect in Consumer Directed Personal Assistance*.

Three years later, after attacks on the program resulting in funding cuts of up to 10% and forced fiscal intermediary (FI) closures, the survey was modified slightly and reissued. In early 2020, the association released the second iteration of the report, *The High Cost of Low Wages: The disregarded impact of balancing a budget on the backs of the disabled*.

Both of these reports primarily detailed the extent of the workforce crisis and the impact it was having on consumers as they tried, and often failed, to receive services in the community.

Since the release of the second iteration of CDPAANYS' report was issued, there have been substantive changes in the landscape of service delivery. First, in December 2019, then-Governor Cuomo announced the Medicaid Redesign Team 2.0 (MRT II). MRT II was officially convened in early 2020 and recommended several changes to the program. Some of these changes, such as limiting consumers to one FI and extending the length of time that a consumer's health assessment lasted from six months to twelve, were recommended and endorsed by CDPAANYS and consumers. Most however were aimed at making it substantially more difficult for consumers to access or qualify for CDPA, including eligibility cuts and changes to the assessment process that advocates have repeatedly argued foster institutional bias and will create bottlenecks in services that will delay care, with potentially devastating effects.

Further, during this time the cuts to CDPA that were enacted as part of the State Fiscal Year 2017-18 budget were finally enacted. Reimbursement cuts in the form of a per member per month rate methodology, a methodology that does not distinguish between FIs in New York City and much less costly Upstate regions, was implemented. Further, a request for offers (RFO) was issued by the DOH, causing substantial confusion among consumers and having an overall chilling effect on the provision of services.

Meanwhile, no action was taken on the worsening workforce crisis, which independent, third-party consulting group Mercer, in their *Healthcare Labor Market Analysis*, found to be the worst in the nation, with an anticipated home care workforce gap of over 80,000 workers by 2025.<sup>1</sup> This gap, according to Mercer, is driven by:

...increased competition from other industries, such as retail, that offer higher pay for similar workers. This has led to an increase in turnover in these roles. Furthermore, while employers in those industries continue to offer higher wages, the national average hourly rate for home health aides and personal aides has stagnated...making recruitment more difficult.<sup>2</sup>

1. Stevenson, M. (2018) *Demand for Healthcare Workers Will Outpace Supply by 2025: An Analysis of the US Healthcare Labor Market*. Mercer, LLC.

2. *Ibid*.

As a result of this crisis, the New York Caring Majority, of which CDPAANYS is on the Steering Committee, worked with Senator Rachel May and Assembly Member Richard Gottfried to create a solution to the issue. Dubbed “Fair Pay for Home Care,” the measure establishes a minimum wage for home care workers, including PAs in CDPA, that is equal to 150% of the highest minimum wage in a region, including those set by a wage board or wage order. This amounts to a statewide minimum wage for home care workers equal to \$22.50/hour.<sup>3</sup>

Through the coalition’s efforts, the Senate, led by Senator Majority-Leader Andrea Stewart-Cousins, included a portion of the increase in their one-house budget legislation. Despite widespread support, the measure was not adopted in the final budget.

The failure to act in the SFY 2021-22 budget had almost immediate consequences as the minimum wage for fast food workers rose to \$15/hour in Upstate New York on July 1. The minimum wage for all other sectors, the wage that approximately two-thirds of PAs earn in this region, remained at \$12.50/hour.

Fully 90% of PAs were reported to earn less than the legally mandated minimum for the fast food sector.<sup>4</sup>

## METHODOLOGY

Upon seeing continued inaction on addressing the workforce shortage, CDPAANYS once again surveyed consumers about the impact low wages are having on their ability to utilize the service. We published the survey in English and Spanish and publicized it through email lists, social media, and member FIs. The survey was open for three weeks from May 17 to June 6, 2021.

During the survey period, CDPAANYS received 211 responses, of which 178 were eligible, meaning that they were consumers or designated representatives receiving Medicaid’s consumer directed personal assistance, and not a similar service from another agency. Of the eligible respondents, 79 identified as male, 93 as female, and 5 preferred not to answer.<sup>5</sup> 73% of respondents identified as Caucasian, 8% as Black or African American, 3% as multiracial, 1% as Native American, and 7% preferred not to answer. 11% of respondents identified as Hispanic or Latino.

Survey participation was voluntary and response rates vary across the state. To correspond more accurately with wage regions, CDPAANYS classified respondents as from New York City (22%), Long Island/Westchester (22%), and the rest of the state (53%). Representation was disproportionately high in the rest of the state region. Respondents were primarily aged 18 to 64 years old (61%) and 65 years or older (31%) with a smaller representation from minors under 18 years old (6%).

Because this is the third time we have conducted this survey, many questions have been presented alongside the results of prior research to indicate the longitudinal impact low wages have had on this service.

3. Fair Pay for Home Care legislation is A.6329/S.5374. As of September 29, 2021 it is in the Health Committee of each chamber. The legislation has bipartisan support of 63 Assembly members and 25 Senators. It is widely supported by providers, consumer advocates, and organized labor.

4. CDPAANYS. (July 2021) Issue Brief: How the fast food minimum wage increase impacts CDPA. CDPAANYS. <https://cdpaanys.org/wp-content/uploads/2021/07/fast-food-wage-survey-issue-brief.pdf> Accessed on September 29, 2021.

5. Approximately 7% of respondents wrote in “hispanic” or “latino” as their identified race. This was captured in more detail in a question about ethnicity so these numbers are not included here.



## FINDINGS

The findings of CDPAANYS' first two reports in this series, from 2017 and 2020, identified a service that was in crisis. The marked difference in results on a comparative basis from these first two reports to the results of this year's survey are, in a word, terrifying.

**These findings paint a bleak picture of a service that has shifted from one in crisis to one that is collapsing.**

Nearly every measure of consumers' ability to effectively utilize the service has deteriorated significantly. At the same time that these New Yorkers were contending with being at higher risk due to the COVID-19 pandemic ravaging the world, they also had to contend with a home and community-based service that, through no fault of their own, could no longer be reasonably relied upon to meet their needs.

## RECRUITMENT

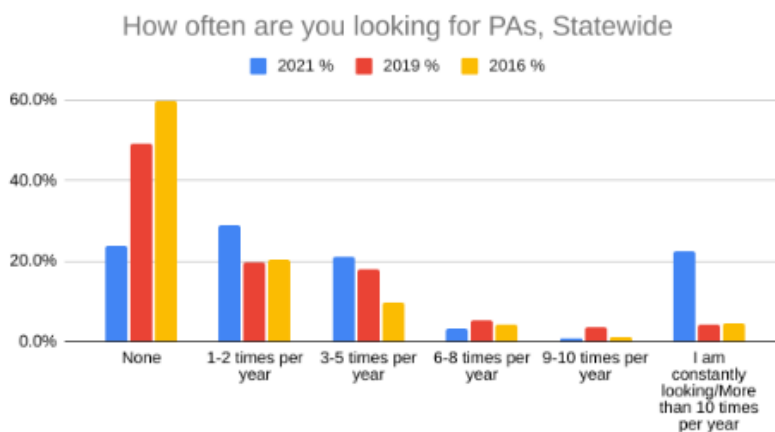
In order for consumers to effectively utilize CDPA, they must be able to recruit and retain a qualified workforce. At a bare-bones level, this requirement exists because regulations require consumers to have a sufficient number of workers, including backup, to use the service. On top of this, many health plans have begun requiring consumers to identify their entire workforce, including formal backup, even before the plan will issue an authorization to the consumer's chosen FI. Beyond legal requirements however, without an adequate workforce, consumers cannot guarantee that their needs, as outlined on the plan of care from the health plan or county, will be met. With needs including such necessities as toileting, eating, and getting into or out of bed, this is a much more important reason why consumers require an adequate, and reliable, workforce.

CDPAANYS has always used the extent to which consumers are looking for workers as a primary indicator of how well they are able to both recruit and retain workers. Disturbingly, this may be the area where we have seen the most significant change since we first conducted the survey in 2016.

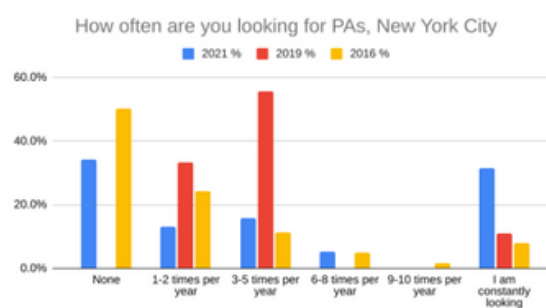
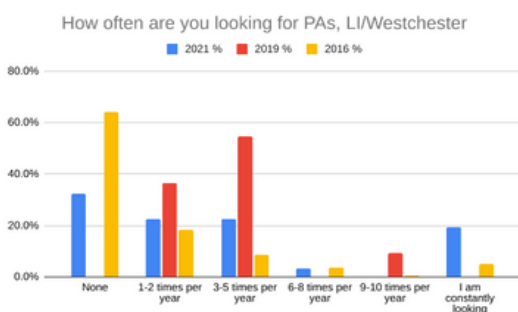
While the wording of this year's question was changed slightly to measure the extent to which a consumer was "looking for" PAs, while in the past we discussed how often the consumer "advertised" for PAs, we feel the similarity of the questions is close enough for the sake of comparison. When that comparison is made, the true extent of the problem begins to emerge.

Consumers who advertise at least once a year are generally indicative of an inability to retain the workers they have. In 2016, 40% of consumers were advertising or looking for workers at least once a year. In 2019, that number increased slightly to 50%. When we surveyed this year, 74% of respondents indicated that they advertised for workers or were otherwise looking at least once during the year. In other words: 74% of seniors and people with disabilities — or 3 in 4 — were unable to retain home care workers in 2021.

What is more telling though is the top of the spectrum. In both 2016 and 2019, 4% of consumers were looking constantly or more than 10 times per year. We noted at the time that even this low number was troubling, because it indicated that almost one in every twenty consumers did not have a reasonable expectation for continuity of care. However, in this year's survey, nearly 25% of respondents were constantly looking for new workers.



In Long Island and Westchester, the number of consumers who were never looking for workers fell by almost a third, while the number who were looking constantly went from 5% of respondees to 19.5%. The problem was the same in other regions of the state. In New York City, those describing themselves as constantly looking also increased four times over the past five years - far and away the largest increase at this side of the scale.



Over the 5-year span, the percentage of consumers outside New York City and its immediate suburbs:

- who reported looking once or twice a year tripled;
- who reported looking three-four times a year doubled; and
- who reported constantly looking increased by a factor of five.

Consumers are most likely to suffer negative, and potentially life-threatening, consequences when they are short staffed. With such large percentages of respondents across the state “constantly looking” for PAs, people are going without needed services. This is not only ethically wrong, it makes no financial sense. CDPA recipients are by definition on Medicaid, meaning that New York will pay the cost of any hospital and/or institutional services that become necessary because of an inability to fill service shifts.

## IMPACT OF COVID-19 ON RECRUITMENT



This survey was conducted in just over one year into the COVID-19 pandemic, and in many ways, no populations were impacted more by the pandemic than seniors and those with disabilities, many of whom quarantined for over a year, not seeing anyone other than their workers. Those most often CDPA consumers knew that if they contracted COVID-19, they were likely to die. They also knew that if they did not receive their home care, they could easily suffer the same fate.

This draws yet further attention to the dramatic increases in the number of people who viewed themselves as “constantly looking” for new PAs. However, to get a real understanding of how COVID-19 impacted consumers, we asked how COVID-19 impacted how often consumers were looking for or hiring new PAs.

How Did COVID-19 impact hiring?	Statewide	LI/W	NYC	ROS
My recruiting and hiring habits and needs remained the same	33.9%	35.5%	34.2%	35.4%
I stopped looking because I was not comfortable bringing in new staff; but I lost staff during COVID-19 and went without	29.4%	35.5%	23.7%	30.5%
I lost staff during COVID and could not replace them, even though I was trying	35.0%	19.4%	42.1%	34.1%
COVID-19 made it easier for me to recruit or retain staff	1.7%	9.7%	0.0%	0.0%

Statewide, about one-third of consumers responding indicated that COVID-19 had no impact on their hiring habits and that their needs remained the same. What we do not know is whether this is because COVID-19 did not interrupt their services, or if it is because they could not recruit or retain staff prior to COVID-19, and this remained the same during the pandemic.

It is deeply troubling that almost three in ten consumers across the state, and over one-third outside of New York City, reported that they stopped looking because they were uncomfortable bringing in new staff, which meant they went without services.

In New York City, either a higher level of desperation or a level of comfort with COVID-19 due to the high rate of infection early on meant that over 40% of consumers continue trying to find new workers during COVID-19; but were unsuccessful. These consumers faced multiple risks. They were constantly interviewing, or even briefly hiring, new staff and thus increasing their risk of contracting the virus. They also risked institutionalization as a direct result of being unable to meet their service needs.

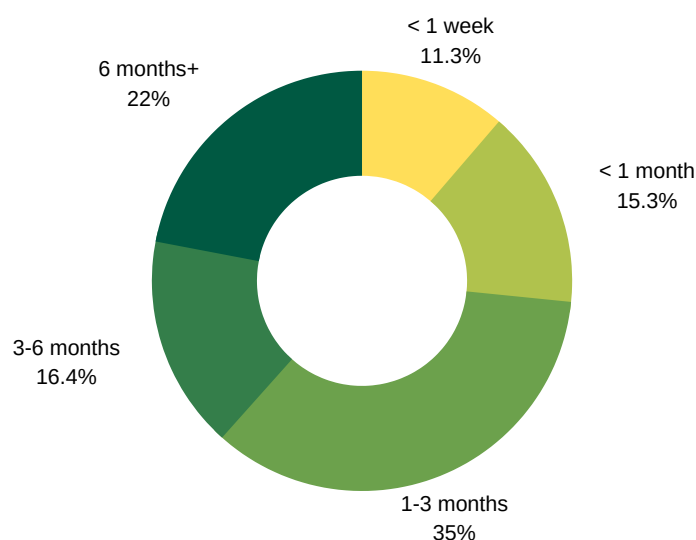
## HOW LONG DOES IT TAKE TO HIRE?

With so many consumers constantly looking for new PAs, it is critical that we understand how long it takes them to actually hire someone when they are looking. Were the consumers searching for PAs during COVID-19 and unable to find someone an anomaly, or is this normal?

Once again, the results point to a crisis that is out of control. Across the state, the percentage of respondents who indicated that it took them over six months to hire a PA has increased dramatically from 2016 and 2019, as has the percentage for whom it took over a year.

On a positive note, the number of consumers who were able to hire a worker within one week has remained fairly steady across all three surveys. This likely indicates that about one-third of respondents have only hired on start-up and came to the program with workers identified.

Offsetting the positive news is that the number of individuals for whom it takes from 6 months to a year, or in excess of a year, to hire a PA is at the same levels as 2016 or 2019 in every instance except one. In the Rest of State region, the percentage of individuals for whom it took over a year to hire a PA did fall from 2019 levels by 3%. However, this number is still 5 times larger than it was in 2016, and the number of consumers in this region for whom it took 6 months to one year to hire jumped by more than three times from 2019 and more than four times from 2016.

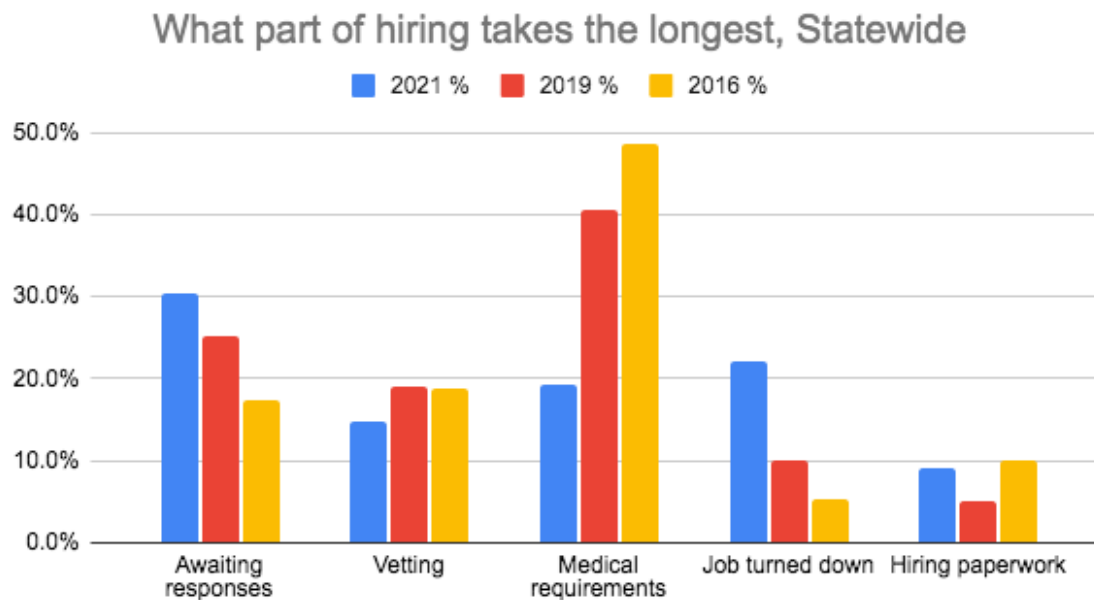


***In 2021, nearly 40% of those surveyed reported that it takes longer than 3 months to recruit a new worker.***

Further, almost four in ten respondents from Long Island and Westchester took over six months to find a worker. This is a 15% increase from 2019, and a massive 24% increase from our 2016 survey.

Given the length of time it is taking consumers to hire new PAs, it is no surprise that so many describe themselves as in a constant state of recruitment. Consumers must be perpetually looking, because if one of their staff quits, there is no expectation that they will be able to fill the position quickly.

Why are consumers taking so long to hire? We asked what part of the hiring process takes the longest. Once again - the answer to this question indicates that the wages, which have fallen dramatically compared to other sectors over the past 5 years, is the reason.



In the previous two surveys, waiting for medical requirements to be fulfilled and vetting or interviewing PAs accounted for a combined 60% or more of responses in each region, and almost 80% of responses statewide. This year, awaiting responses to an advertisement and candidates turning down offers far outpaces every other category, except in Long Island and Westchester where medical requirements still had the highest response.

The Long Island and Westchester region's response is difficult to explain, as it is worth noting that one reason medical requirements may have decreased so significantly as a delay statewide is that the Department of Health has had health reassessments suspended for the past year and a half due to COVID-19. This could indicate that in Long Island and Westchester, high turnover continues to cause consumers to hire additional PAs. If this is combined with the repeatedly high levels of COVID-19 throughout the region, where New Rochelle in Westchester was the one of the original hot spots nationally, it could explain why meeting medical requirements remains disproportionately high in the region.

However, the dramatic increase in time it takes for consumers to hire their PAs, combined with the seismic shift in what part of the hiring process takes the longest, is of deep concern and means that retaining PAs becomes absolutely critical.

WORKFORCE RETENTION

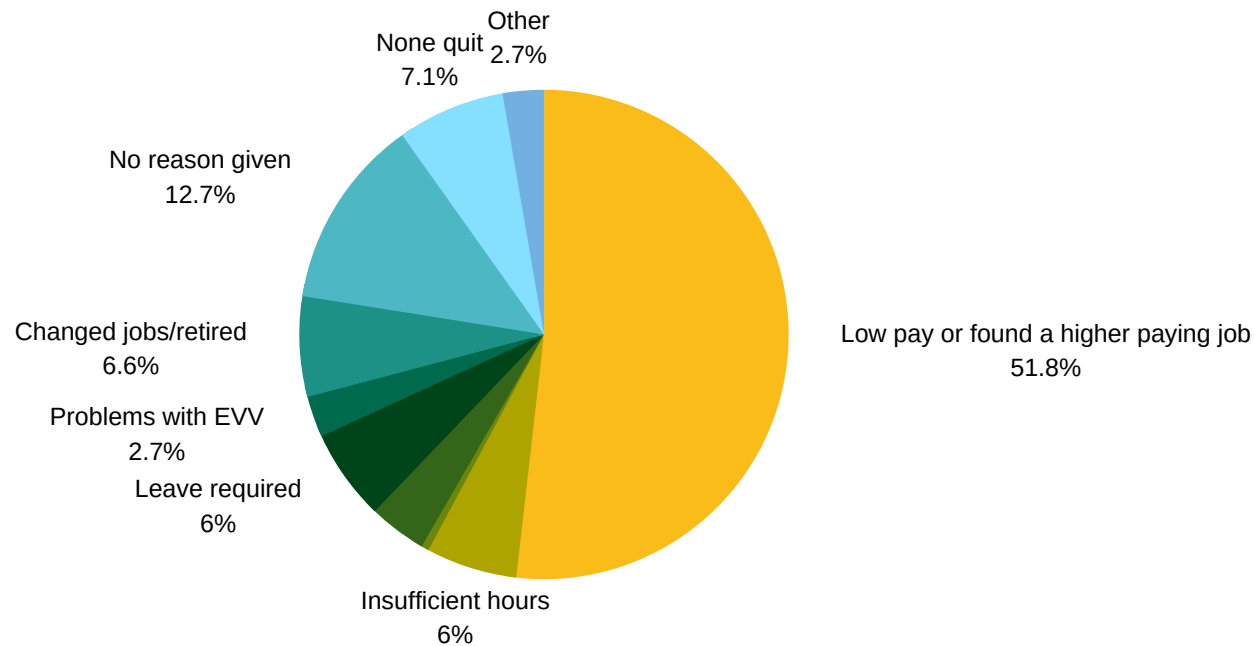
Because of how critical retention of PAs is, we must understand how likely it is that PAs stay on the job. Each year, we have asked consumers to think about the last five PAs who are no longer with them and identify how many were fired versus how many quit.

When this data is examined, we see that the number of consumers reporting that three out of their five PAs quit has increased by almost 10% over the span of the surveys. The number reporting four of the five quit doubled, from 4.5% to 9% of consumers. Most indicative of the fact that New York’s HCBS system is collapsing however was that the number reporting that all five workers quit jumped to 19.6% of respondents, over five times higher than when the survey was first taken in 2016, and over seven times higher than the 2019 results. With minor changes, these numbers bear out in each region of the state.

The reasons people quit are clear. Statewide, one out of every two PAs told the consumers they had worked for they quit due to low wages. Not being provided with enough hours to work is another indicator of low wages, as PAs will rely on high hours to compensate for low wages. When this indicator was factored in, three out of every five PAs left due to an inability to earn enough money. At one out of every eight PAs who quit, those who did not provide a reason were the next highest group. Only one out of every 14 indicated that no workers had quit.

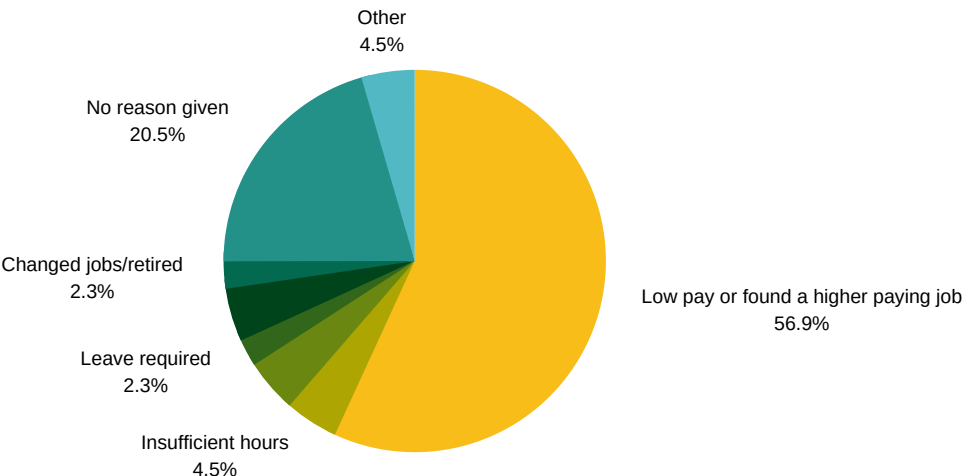
When broken out by region, in every region, at least twice as many PAs identified low wages as the reason they quit. By far the worst, the Rest of State region saw three out of five PAs tell consumers they were quitting due to low wages. Here, most PAs were not even willing to continue if they could work more hours, as only one in twenty said low hours were the primary reason for quitting. Slightly more than one in ten did not report a reason why they were quitting, and a mere one in fourteen consumers reported that no PAs had quit.

Why did your PA quit? Statewide



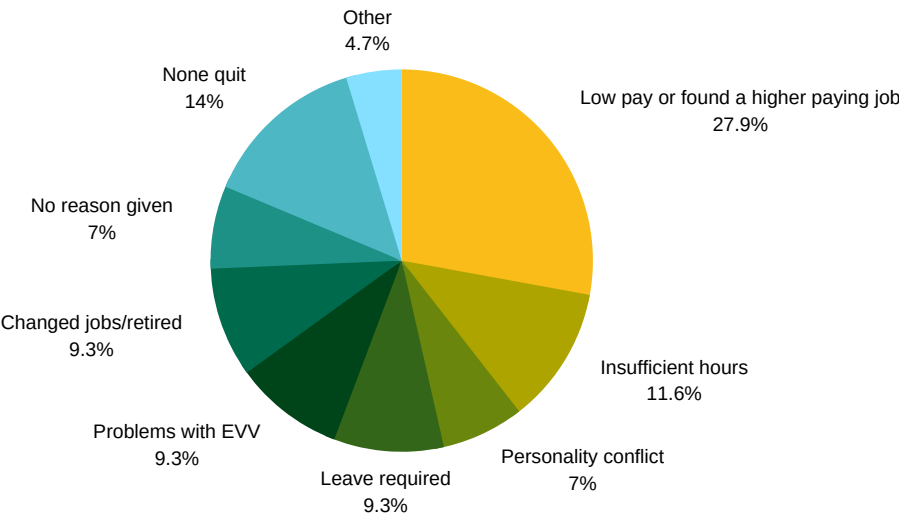
Long Island and Westchester were not far behind the Rest of State region. Here again, nearly three out of every five consumers reported PAs quitting due to low wages. Again, only about one in twenty reported quitting due to not enough hours, indicating that people were unwilling to do the work for the pay provided. One in five PAs did not provide consumers with a reason as to why they were quitting; however, shockingly, no consumers indicated that a PA had not quit.

Why did your PA quit? LI/Westchester



Even in New York City, where the minimum wage is equal to the fast food minimum wage, consumers reported that one in four PAs quit due to low wages. When an inability to work enough hours is factored in, that jumps to two out of every five PAs quitting due to an inability to earn enough. About one in seven consumers in New York City reported that no PAs quit, while about one in 14 did not provide a reason.

Why did your PA quit? NYC

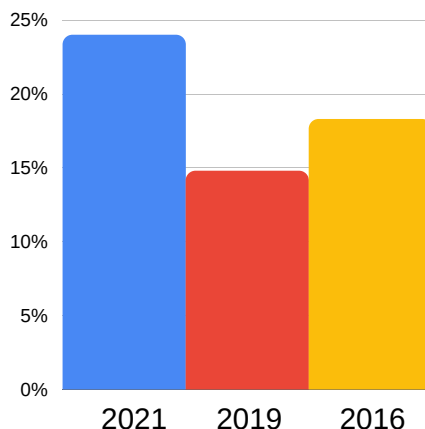


Given all of this data, it is to be expected that consumers are more desperate than ever to do anything in an attempt to keep their PAs from quitting. While Federal Medicaid rules tend to prohibit any kind of formal cost-sharing, except in limited situations such as prescription drug coverage and non-emergent hospital visits, we know that many consumers have resorted to supplementing their PAs wages in order to convince them to stay, or take the job to begin with.



We asked consumers whether they are supplementing their PAs wages, and if so, by approximately how much. The answers, once again, are cause for concern.

### % Consumers who supplement PA wages, Statewide



CDPAANYs, and our member FIs, do not support or encourage consumers to supplement PA wages. However, we also cannot ignore the fact that it is occurring. Given that those who use CDPA are on Medicaid, usually on fixed incomes, it begs the question: are we demanding that impoverished seniors and disabled New Yorkers subsidize their own Medicaid services?

While it is still a minority of consumers across the state who report doing so, the answer is clearly yes. And it is an answer that is getting louder. Across the state, we saw the percentage of consumers who report that they do supplement pay for their PAs increase from the previous high of 18% in 2016 to almost 25% this year. Since the Long Island and Westchester region saw an overall decrease in the percentage of respondents reporting that they supplement wages, the increase overall took place in New York City (up 6% from the previous high in 2016) and the Rest of State region, where those supplementing more than doubled to a point where now one in four consumers reported supplementing wages.

The degree to which consumers offered additional wages varied. Several consumers reported that they reimbursed PAs an additional \$5/hour. Some reported bringing PAs up to the fast food minimum wage of \$15/hour. However, in some instances, consumers were clearly spending money they do not have just to receive their basic services - services they are entitled to under Federal and State law.

A number of consumers reported spending between \$200 and \$500 per week on additional wages for their workers. The highest reimbursements were two people who provided extra wages totaling \$650/week, and one each who provided additional wages totaling \$700 and \$800/week. This puts consumers in a position of spending over \$3,200 of their own money to receive basic services.

Presumably, many of these supplements are from family and/or friends who want to ensure coverage, since these levels of payments would put most consumers above the Medicaid eligibility thresholds; however, focusing on the “how” misses the broader point that it is occurring at all.



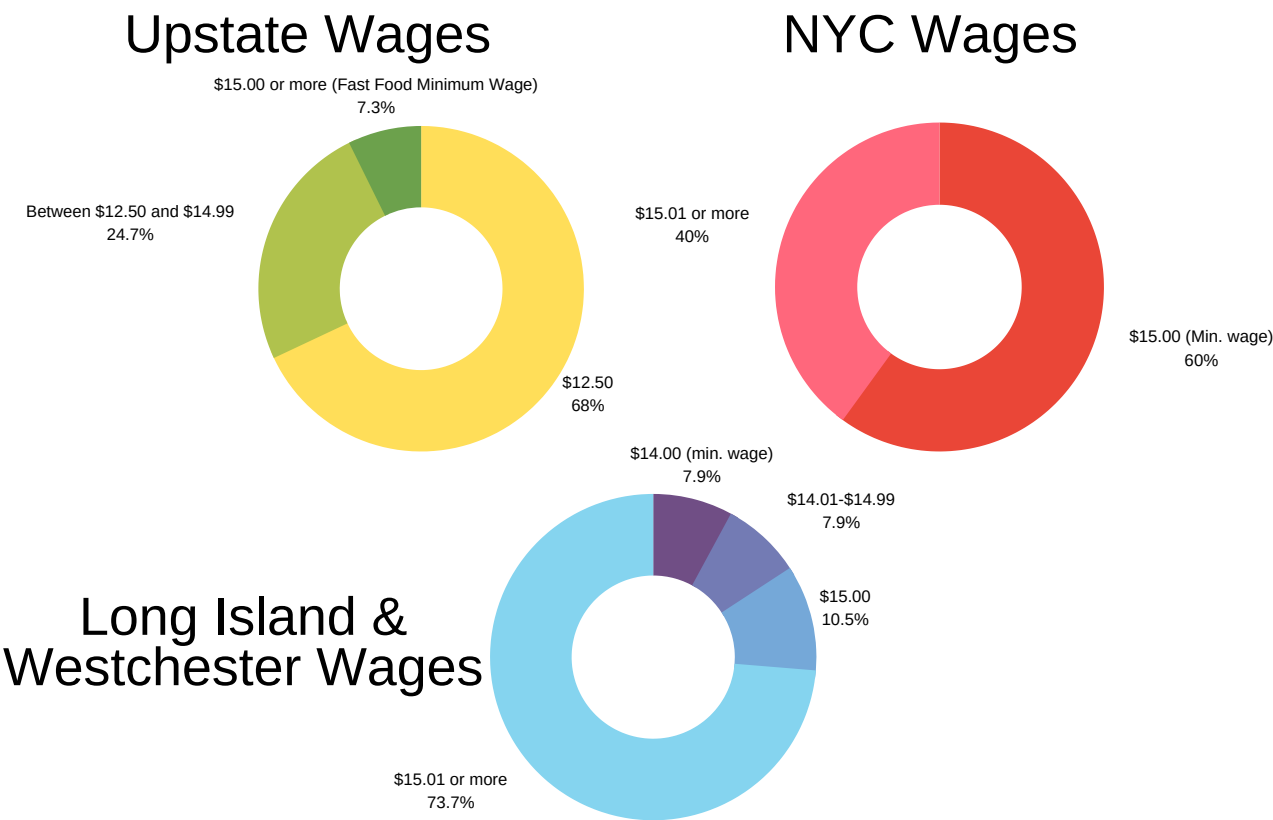
THE STATE OF WAGES

The data comes more into perspective when the state of wages throughout the state is taken into account. In 2005, PAs in New York City, Long Island, and Westchester were making 166% of the minimum wage. Many PAs throughout the rest of the state were also paid significantly more than this wage as well. As recently as 2010, FIs throughout New York City, Long Island, and Westchester were paying PAs at least 139% of the minimum wage at that time, again, with PAs throughout the rest of the state also generally earning more than this minimum.

Unfortunately, a by-product of the state’s move raising the minimum wage across the state was that home care, and the role of a PA by extension, became a minimum wage job. Further, because there is a wage order in place requiring that fast food workers at large chains make at least \$15/hour across the state, many home care workers, especially in the “Rest of State” region, now make significantly less than their counterparts working in fast food.

When we asked consumers how much they can pay their PAs, the results confirmed this. Long Island and Westchester reported the best results by far, with 75% of PAs able to earn over \$15/hour. However, in New York City, where the minimum wage is \$15 for all workers, three out of every five workers are earning the minimum.

Outside the NYC metro area, the situation is most dire. Over two-thirds of PAs in this area are at the minimum wage of \$12.50/hour, and less than one in ten earn the same or higher per hour than the fast food minimum wage.



The relatively higher wages in Long Island and Westchester are likely accounted for by what is often a higher reimbursement rate for FIs in this region. Those agencies who provide services in New York City and Long Island are often reimbursed at one rate for the provision of services in each region.<sup>6</sup> The higher reimbursement indicates that, when FIs have the opportunity to invest more in PA wages, they do so.

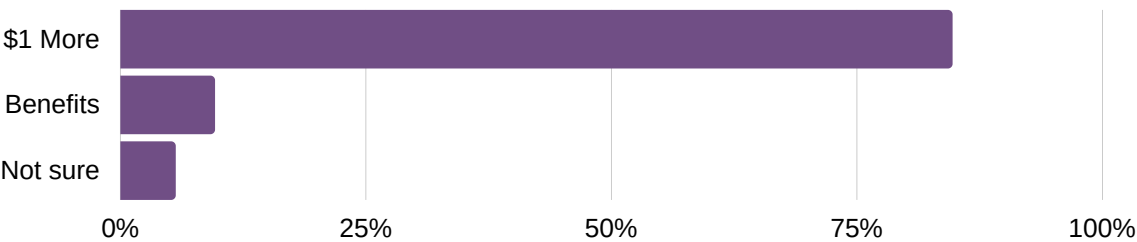
These higher wages likely also account for what would otherwise be classified as anomalies in other portions of the data, such as the lower levels of consumers supplementing wages in this region. This explanation would likely account for what we saw in the next question we asked, which was whether consumers thought that a \$1 increase in wages or additional benefits would be more helpful in allowing them to better recruit and retain PAs.

As the workforce crisis has been discussed over the years, the issue of wages vs benefits has been one that has been much discussed. Associations, advocacy groups, labor unions, and policymakers have often contended that as much, if not more, progress could be made in resolving the workforce crisis if increased benefits, such as health insurance, retirement plans, or even transportation to and from clients, were more generous.

When CDPAANYS asked this question, with a \$1 increase in wages posited against an increase in benefits, the answer from consumers was overwhelmingly clear that an increase in wages was what is needed.

Statewide findings

Which would aid PAs more: a \$1.00/hr raise or additional benefits?



Statewide, 85% of respondents indicated that a modest \$1/hr increase in wages would be more useful in helping them recruit and retain a high quality workforce than additional benefits. This number was highest in the “Rest of State” region, with nine out of ten respondents indicating the wage increase was more needed. However, even in New York City, where wage increases came in lowest, three out of four respondents thought the wage increase would be more helpful, and “I don’t know” tied with “additional benefits” with one in eight respondents each.

While some will argue that consumers are not the workers themselves, consumers are the ones recruiting their workers. They hear directly from potential PAs why they are refusing to take a potential job, and they hear from PAs who are quitting as to why they are quitting. The views of these PAs are critical firsthand information to inform this discussion moving forward, free of any self-interest except that which would ensure that they have a quality workforce in place to provide the basic services they require to live independently in the community.

6. This information was garnered from conversations between CDPAANYS and member fiscal intermediaries who provide services in Long Island, Westchester, and New York City. It does not apply to all agencies or all plans

## DISCUSSION

In 2017 and 2020, CDPAANYS spoke about an industry in crisis. This survey demonstrates that after five years of reimbursement cuts, eligibility cuts, and a failure or unwillingness to hold managed care plans accountable, CDPA, and by extension home care overall, is in a full-scale collapse.

Over a period where consumers and caregivers were forced to contend with a “hundred-year pandemic” in COVID-19, and patients in long-term care institutions were demonstrably at substantially greater harm than those receiving such services in the community. This was despite the assertions of the former Governor, whose claim that, “...you can argue that [seniors in nursing homes] are safer than a senior citizen at home who is receiving care at home,”<sup>7</sup> only told those providing and receiving services in the community that he did not care about them.

By every measure, and across every region of the state, the picture is dramatically worse today than it ever has been. More consumers are in a state of perpetual recruiting than they ever have been, to a point where they were even looking for PAs, often unsuccessfully, during the height of the pandemic in New York City at a time when we knew very little about the virus and anxiety was also at its apex.

Not only are consumers constantly recruiting workers, it takes substantially longer to hire than years past. Further, in previous iterations of the report, consumers could hire workers, but faced delays with medical requirements or paperwork. Now, the strong majority of consumers either do not get responses to advertisements to begin with or have potential PAs turn down the job once they find out what the wages are.

When consumers can finally hire a PA, it is increasingly likely that the PA will quit, which starts the process all over and explains why the consumer is in a constant state of recruitment. Consumers are so desperate that they are resorting to supplementing the wages of their PAs with money they do not have, sometimes at a cost of as much as \$750 or more per week.

Those who use CDPA are seniors and people with disabilities who require assistance with activities of daily living that most people take for granted; but, which for them are critical to their ability to live independently, work, participate in their communities, and live vibrant lives to their fullest potential.

CDPAANYS agrees strongly that lifting the wages of fast food workers to \$15/hour was a needed policy step to ensure that these workers would make a living wage. We also concurred with the state’s efforts to raise the minimum wage overall, although we disagreed with the differentials that created up to four different minimum wages throughout the state, with even more differences when the fast food wage order was factored in.<sup>8</sup>

7. Todd, Chuck. (June 28, 2020). NY Gov. Cuomo: Government 'Failed Effort To Stop The First Wave'. Meet the Press. NBC News. Accessed from YouTube on 10/1/2021. [https://www.youtube.com/watch?v=mlucDinlomi&ab\\_channel=NBCNews](https://www.youtube.com/watch?v=mlucDinlomi&ab_channel=NBCNews).

8. When the minimum wage was raised in the SFY 2016-17 budget, it was staggered. Large employers in New York City saw the fastest implementation, reaching a \$15/hr. minimum wage on 12/31/2018. Small employers (those with less than ten) reached the \$15/hr. level on year later on 12/31/2019. As of October 1, 2021, the minimum wage in Long Island and Westchester is \$14/hr. and is scheduled to rise to \$15/hr. on 12/31/2021. The minimum wage on October 1, 2021 in the “Rest of State” region was \$12.50/hr. It was recently announced that this wage will climb to \$13.20/hr. on 12/31/2021, with additional increases to potentially take place annually until it reaches \$15/hr. Effective 7/1/2021, the fast food minimum wage rose to \$15/hour in the “Rest of State” region, making that wage \$15/hr. statewide. New York State Department of Labor. (Accessed on October 1, 2021). New York State’s Minimum Wage. <https://www.ny.gov/new-york-states-minimum-wage/new-york-states-minimum-wage>

## THE HIGH COST OF LOW WAGES

The unintended, or potentially intended, side effect of this policy was that PAs and home care workers overall went from making approximately 166% of the minimum wage to minimum wage. In fact, what once was a job that could lift a worker into the middle class became a job that was reserved for those on the bottom rungs of the economic ladder.

Since retail and fast food workers, two other prominent low-wage workforces, could raise the price of their goods and services in order to raise wages, they did so. Recently, Amazon announced that they will be raising the entry level pay for their warehouse employees to \$18/hour.<sup>9</sup> Similarly, a warehouse package handler at FedEx is currently offered starting wages of \$17.00/hour in Albany, NY.<sup>10</sup> In response, many fast food establishments are offering above the required \$15/hour minimum wage.

Fiscal intermediaries do not possess the ability to compete for workers in this way. Since CDPA only exists in Medicaid, FIs have no private-pay consumers. Further, commercial insurance, Medicare, worker's compensation, and other payers are also not included. The only method of reimbursement agencies have are those set directly by the state or those set by managed care companies acting on the state's behalf. Over the past five years, these rates have faced significant cuts. In 2019, the state cut reimbursement rates for FIs by \$150 million. While this cut was purportedly just on administrative services, it ended up impacting wages because subsequent cuts from plans impinged FIs ability to offer overtime and other payments for PAs.

At the same time that the service was facing significant financial cuts, the DOH was also working to dramatically reduce the number of agencies that can operate as FIs.<sup>11</sup> In pushing back against advocacy efforts by CDPAANYS, consumers, FIs, and advocates from across the state, the DOH caused even further harm to the workforce crisis by repeatedly talking about the high number of "bad actors" in the program and diminishing the hard work done by PAs in CDPA.

9. Fickenscher, L. (2021, September 14). Amazon boosts starting hourly wage to \$18 amid ongoing hiring rush. *New York Post*. <https://nypost.com/2021/09/14/amazon-boosts-starting-hourly-wage-to-18-amid-hiring-rush/>

10. FedEx Ground. (n.d.). Warehouse Package Handler. *FedEx.Com*. Retrieved October 1, 2021, from <https://groundwarehousejobs.fedex.com/groundwarehousejobs/jobs/25736-506465?lang=en-us&previousLocale=en-US>

11. The SFY 2019-20 budget implemented an RFO process. This led to substantial advocacy by FIs, consumers, and PAs to "Save CDPA."

The state's negative attitude towards this sector continue. In the past several months, the state received an estimated \$2.15 billion of enhanced FMAP rate under the American Rescue Plan (ARP).<sup>12</sup> When passing this enhanced rate, Congress specified that "states must use the state funds equivalent to the amount of federal funds attributable to the increased FMAP to implement or supplement the implementation of one or more activities to enhance, expand, or strengthen HCBS under the Medicaid program" and that "federal funds attributable to the increased FMAP must be used to supplement existing state funds expended for Medicaid HCBS in effect as of April 1, 2021."<sup>13</sup>

However, in submitting the plan to the Centers for Medicare and Medicaid Services (CMS), the DOH proposed to use \$415 million of the approximately \$1.2 billion appropriated to it to "Support program growth in personal care and CDPAP to ensure capacity."<sup>14</sup> Despite a title that made it sound as if this program was raising capacity, DOH was clear in their description that was not the case.

*While the growth rate of these programs has remained high, structural factors—such as workforce capacity limitations—have served to limit growth. However, by permitting New York to address many of these structural factors and promote the capacity and accessibility of HBCS, funding under Section 9817 of ARPA will work to create natural growth in PCS and CDPAS based on pertinent minimum needs criteria.*<sup>15</sup>

In their own description of the proposal, the DOH acknowledges that "structural factors - such as workforce limitations..." have been used to keep CDPA and personal care from growing at rates greater than they already are. This action was compounded by a \$55.35 million proposal that would have the DOH invest in training for nursing home workers as a means to lifting up the HCBS sector and \$46.9 million that was proposed to implement the Community First Choice Option (CFCO), an Affordable Care Act program that was supposed to have been implemented in 2015 when the state received approval of their state plan amendment implementing it.<sup>16, 17</sup>

The state's actions, coupled with their language, indicate that the previous administration actively worked to enhance, not limit, the "structural barriers" that have created this workforce crisis, a crisis that they publicly only acknowledged existed in the HCBS spending plan for ARP.

For over a decade, CDPA and other HCBS services in New York have been systemically cut and demonized. With simultaneous actions being taken to lift workers in other industries whose reimbursement is not driven by the state, it is not difficult to determine how New York found itself as the epicenter of the national workforce crisis that is plaguing HCBS services nationwide.

12. New York State Department of Health. (July 2021). *Spending Plan for Implementation of American Rescue Plan Act of 2021, Section 9817: Additional support for Medicaid Home and Community Based Services (HCBS) during the COVID-19 Emergency.* [https://www.health.ny.gov/health\\_care/medicaid/redesign/hcbs/enhanced\\_funding/docs/2021-07-08\\_hcbs\\_spending\\_plan.pdf](https://www.health.ny.gov/health_care/medicaid/redesign/hcbs/enhanced_funding/docs/2021-07-08_hcbs_spending_plan.pdf). Accessed on October 5, 2021.

13. 1319 - 117th Congress (2021-2022): American Rescue Plan Act of 2021, H.R. 1319, 117th Cong. (2021), <https://www.govinfo.gov/app/details/BILLS-117hr1319enr>.

14. Department of Health, spending plan.

15. Ibid.

16. Ibid.

17. New York State Department of Health. (2015). *SPA 15-60. Community First Choice: Personal attendant services and supports.* [https://www.health.ny.gov/regulations/state\\_plans/status/coverage/approved/docs/app\\_2015-10-28\\_spa\\_15-60.pdf](https://www.health.ny.gov/regulations/state_plans/status/coverage/approved/docs/app_2015-10-28_spa_15-60.pdf). Accessed on October 5, 2021.

## RECOMMENDATIONS

If New York is to learn the lessons of the past and move forward to rebuild its home and community-based services, it must commit to strong investments in this sector and a fundamental rethinking of the long-term care system overall. The services must be viewed as the necessary, life-saving and quality of life enhancing services they are, not a burden for the state to bear and a cost driver.

Those most in tune with the needs of personal assistants - the consumers who hire and supervise them - have told us that small steps will not suffice. The state must think and act big to solve this crisis.

### FAIR PAY FOR HOME CARE

The primary step that must be taken is to affirmatively invest in HCBS services by enacting and implementing Fair Pay for Home Care.<sup>18</sup> Fair Pay for Home Care represents the largest investment in the home and community based sector in decades, an investment that has proven necessary in the wake of COVID-19, when the world's eyes were opened to the inadequacies of nursing homes.

The bill restores the wages of personal assistants, personal care aides, and other HCBS workers to 150% of the highest minimum wage in a region, or \$22.50/hr., approximately the level they were at prior to the first Medicaid Redesign Team and a decade's worth of neglect. However, the legislation also ensures that the new wages are funded, introducing accountability for managed care plans and the state to ensure that FIs and other home care providers are reimbursed sufficiently for the costs they incur.

Chief among these additional reimbursement requirements is reconfiguring the way in which the state's per member, per month reimbursement for FIs is calculated. Currently, the state employs one rate for providers, whether they are in New York City or Essex County. This one size fits all approach ignores the dramatically higher costs of doing business in Downstate New York and is jeopardizing the long-term viability of these agencies.

18. *Fair Pay*, A.6329, [https://www.nysenate.gov/legislation/bills/2021/A6329#:~:text=A6329%20\(ACTIVE\)%20%2D%20Summary,medicaid%20and%20managed%20care%20plans](https://www.nysenate.gov/legislation/bills/2021/A6329#:~:text=A6329%20(ACTIVE)%20%2D%20Summary,medicaid%20and%20managed%20care%20plans).

## TRANSPARENCY REFORM

The state must also work to introduce transparency and accountability with managed care plans. Fair Pay for Home Care, by setting a minimum reimbursement rate for providers, would begin this process.

However, A.8173 (Gonzalez-Rojas)/S.7372 (Hinchey) would require the state to report to the public how many people are using community-based long-term care services across the state, as well as how many hours, on average, their members are receiving. This will allow people to identify which plans are outliers, either providing more services than most other plans, or dramatically fewer. This is information that used to, in part, be provided by the state until services were shifted to managed care plans, and the lack of transparency has played a large role in the continued degradation of these services.

## STOP MRT II ELIGIBILITY CUTS

Finally, the state must undo the devastating changes to eligibility and access created by the second Medicaid Redesign Team (MRT 2). Enacted just as the state was undergoing the initial wave of the COVID-19 crisis, these changes cut eligibility by requiring that seniors and those with disabilities require physical assistance with at least three activities of daily living (ADLs), unless they had Alzheimer's Disease or dementia, in which case they needed physical or supervisory assistance with two or more ADLs.

The MRT 2 also required that consumers no longer receive medical assessments from their own doctors, but use state appointed medical professionals instead. For those in need of twelve or more hours of service per day, this requirement would be doubled with a new "high needs review" to determine whether or not they are safe in the community.

These cuts will limit the accessibility of services to many of those who need them most. In the best case scenario, they will prove pennywise and pound foolish, as individuals who could be served somewhat inexpensively are forced to a point where they are in need of many more services, or institutionalization. In the worst case, these cuts will actively prevent people from accessing necessary services in the community - even if we take the necessary steps to improve the workforce.

All of the eligibility and accessibility cuts from MRT 2 must be eliminated if the state is to truly prioritize and lead on the provision of HCBS.



## CONCLUSION



Advocates have warned for years of a pending crisis in consumer directed personal assistance and home care services overall. This survey, the third we have conducted, shows that the system is no longer in crisis; it is in full collapse. People across the state are unable to hire new workers, and when they can, those workers soon leave because the wages are too low. Further, unlike past years, this problem exists in every corner of the state as seniors and disabled New Yorkers across the state are reporting an inability to meet their needs in the community.

If the state does not immediately move to invest in home and community-based services and increase wages, the reality is that nursing homes will be turning people away because of a lack of beds. While again shifting a reliance to nursing homes is a tragedy in and of itself, thousands will die as a result of going without needed services. And those who continue to do this job will suffer; unable to put food on the table, pay rent, or meet basic life expenses.

**IN NEW YORK STATE, A STATE THAT PRIDES ITSELF ON  
BEING A PROGRESSIVE BEACON FOR THE REST OF THE COUNTRY,  
THIS IS UNACCEPTABLE.**